

Premiering FAS 101 Curriculum FASD: Disabilities of Discovery: Insights on Brain-Based Disorders

One of the original goals established for Alaska's Comprehensive FAS Project was to improve lifelong outcomes for individuals with FASD through improved services. To accomplish this goal, training of all appropriate service providers is critical. The key to making long-lasting change is through the development of comprehensive, interactive and relevant training what is FASD, how does alcohol impact the developing brain, and what strategies will help serve this population better, with improved outcomes?

Training can both begin to change the paradigm related to this disability (brain damage vs. behavior problem), and it can begin the process of systems change within our existing service delivery systems. Services to individuals with fetal alcohol spectrum disorders now and in the future will be provided by the existing service delivery systems-education, developmental disabilities, juvenile justice, child protection, health care, public assistance, vocational rehabilitation, substance abuse treatment, mental health and corrections, to name a few. If we expect to improve how services are provided to this population of children, youth, adults and their families, change needs to occur within these existing service systems.

Through a contract with the

UAA Family and Youth Services Training Academy, our FAS 101 curriculum has been completed. FASD: Disabilities of Discovery: Insights on Brain-Based Disorders is a comprehensive curriculum to educate diverse groups of individuals, from many disciplines and many walks of life about the complexities of fetal alcohol spectrum disorders. The curriculum outlines exactly what fetal alcohol spectrum disorders are, how alcohol impacts the developing fetus, what parts of the brain are specifically impacted and how that brain damage equates into behavior and learning disabilities. The 4-hour curriculum includes a PowerPoint presentation, a written Presenter's Guide, and resource materials to use with the curriculum.

Developing a thoughtful and carefully designed process for distribution of the curriculum is a substantial challenge. At this time, the curriculum will not be available for mass distribution. Instead, we are establishing a FASD Training Certification program, selecting a core group of individuals who will receive a week-long training to immerse potential trainers in the FASD material, receive instruction on how to be an effective trainer, prepare and present units of training and develop a training plan for the coming year.

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The first FASD Training Certification program is scheduled for June 23-27, 2003 at the University of Alaska Anchorage.

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(...FAS 101 continued from page 1)

Eighteen individuals will be selected, through an application process, to attend this 5-day training. Applications for this program are available on our website at *www.hss.state.ak.us/fas/* or you can call our office to receive an application. Completed applications are due in our office by 4:30 PM Friday, May 16th.

The cost of travel, lodging and meals will be covered for each selected participant. Each participant who completes the training, passes the staff/peer review and receives a "certificate" may be eligible for a \$5,000 mini-grant to assist in training associated costs such as materials, resources, presentation equipment, supplies, copying, room rental, and staff time and would be required to provide six (6) FAS 101 trainings during FY 2004.

We are very excited about this new program and believe that by developing local community-based expertise, we can more effectively train service providers across the state and across disciplines, which will begin the process of changing the paradigm of thinking about this disability. This, in turn, will change how our systems approach their work with individuals affected by prenatal exposure to alcohol.

Coming up next—a web-based self-study program using the same information and resources from FAS 101! ❖

Key Campaign

The annual Key Campaign was held in Juneau February 25–26 providing an opportunity for disability advocates from across Alaska to inform and educate lawmakers, policy-makers and the general public about the unique needs of individuals with disabilities and their families. Roxana Sawyer and her daughters Jolene and Leona traveled to Juneau to educate folks about FASD, meeting with legislators and joining in the rally at the Capitol.



Overview of Department Reorganization

In early March DHSS Commissioner Joel Gilbertson announced a major reorganization of the Alaska Department of Health and Social Services, including internal consolidations, combining of programs and moving five programs from the Departments of Administration and Education and Early Development to DHSS. While it will begin July 1, 2003, the complete reorganization will be done in phases that will take up to two years. The goal of reorganization is to increase efficiency, maximize federal Medicaid dollars available, and to enhance the quality of health and social services for the people of Alaska.

The Department will be divided into eight (8) divisions including Health Care Services, Alaska Longevity Programs, Public Health, Senior and Disabilities Services, Public Assistance, Administrative Services, Juvenile Justice and Behavioral Health. In addition, the former Division of Family and Youth Services will now be included in the Office of Children's Services, adding Healthy Families Alaska, Infant Learning Programs, WIC and Behavioral Rehabilitation Services.

The Office of Fetal Alcohol Syndrome (FAS) will be moved to the Division of Behavioral Health with Mental Health Programs, Alaska Psychiatric Institute, Residential Psychiatric Treatment Centers, Inpatient Psychiatric Care, and Substance Abuse Programs. The goals of Alaska's Comprehensive FAS Project will remain consistent throughout the reorganization, continuing the work we began in 1998.

Through this reorganization Commissioner Gilbertson states that "Alaskans will get better customer service, and DHSS will be in a stronger position to deliver quality services in very tough financial times for the State." We will all be working hard to make this reorganization as smooth and seamless as possible!

Dan Dubovsky back in Alaska!

Daniel Dubovsky, FAS Specialist with the CSAP FAS Center for Excellence traveled to Alaska in February/March for two weeks of training and presentations. During his time here he made presentations in Anchorage. Kotzebue, Kodiak, Fairbanks and Juneau and was featured in a front page article on FASD in the Juneau Empire! Many thanks to Dan for traveling so many miles and to so many communities helping all of us increase our knowledge about fetal alcohol spectrum disorders.





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Kids and parents alike enjoyed a variety of fun-filled activities at this year's FASinating Families Camp!

News from FAS Innovative Grantees

Volunteers of America

This year's FASinating Families Camp, held December 27-30 at Solid Rock Bible Camp in Soldotna, Alaska, was another huge success. Featured presenters, Angelina Cruz and Jessica Glebmann from Thunder Spirit Lodge in Minnesota provided over 14 hours of workshops and presentations to the 17 families who attended camp. Presentations were available not only for parents, but also for youth attending camp both of which were well received. Another fun camping activity included a gathering of local mushing club members and their dogs providing sled rides for the children. Mushers took extra time to let the children interact with the dogs, pet them and ask questions. Another popular presentation was an interactive session with two musicians who allowed the kids to use drums, march, sing and dance. During respite times, children participated in a variety of crafts, games, and recreational activities - including sledding and a unique indoor "bungee run"! Childcare was provided for babies and toddlers, chair massage was offered, a trip to a local indoor pool, and time for making family fleece blankets rounded out the camp experience. Based on positive family feedback, Volunteers of America plans to continue to hold FASinating Families camp over the winter school break, so see you next year!

Alaska Foster Parent Training Center

Through a partnership between the Alaska Foster Parent Training Center (AFPTC) and several other community based groups, a variety of trainings and activities have been sponsored in the Fairbanks area. Interest from a local Elks club led to the service organization sponsoring an all day FASD training and providing lunch for all participants. Over 90 people participated in the training, and AFPTC was able to provide travel scholarships to 11 participants. Through this event a partnership with the Elks club blossomed and the service club went on to purchase Palm Pilots and keyboards for six young adults with FASD! The Elks also contacted the Fairbanks City and Borough Mayor's office and were successful in having the city declare the 3rd Saturday in February as "FAS Awareness Day". The Foster Parent Training Center followed up these events by helping to host training by Dan Dubovsky, national presenter in FASD. Thanks to a strong partnership between the FASD projects in the Fairbanks area, community interest in FASD is at an all time high. Our hats also go off to the dedicated membership of the Fairbanks Elks club for making FASD a priority project for their group and their community.

Stone Soup Group Family Support Project

Cheri Scott, coordinator for the FASD parent support project has been busy developing a number of resources available to families and community groups statewide. The Stone Soup Group is happy to announce the following services are now available:

- ✓ A toll-free support line 1-877-786-7327 (1-877-STOP FAS) for families and caregivers raising children with FAS.
- Mini-grants and how-to manuals for setting up community-based FAS Family Camps.
- How-to manuals for beginning a family support group in your community.
- ✓ A web-site http://www.stonesoupgroup.org/fas that provides information about parenting children with FASD, upcoming trainings, available resources, and research regarding best practices.
- ✓ A list-serve, www.groups.yahoo.com/group/fasparent, created exclusively for Alaskan parents and caregivers of children and adults with prenatal exposure to alcohol.

For more information about any of these services, contact Cheri Scott at the Stone Soup Group at (907) 561-3701.∞

FAS Community Team Highlights

The Ketchikan Area FASD Community
Diagnostic Team is a well developed
partnership between several key agencies
in the Ketchikan community: Ketchikan
Indian Corporation, Gateway Center for
Human Services, Community Connections,
Callisto Pediatrics, and the Ketchikan
Gateway Borough School District. These
agencies all work together to ensure



comprehensive and multi-disciplinary assessments occur. After more than a year of planning, outreach and education, the Ketchikan Area FASD Diagnostic Team began conducting diagnosis in the summer of 2002. Team members from across the Ketchikan community and from outlying areas attended training at the University of Washington FAS DPN in February of 2002, and held their first clinic just four months later! Since that time, the team has completed more that 18 assessments, and has worked with the Ketchikan TRUST Community Support team to tackle the issue of FAS in their area. This group, comprised largely of family members of individuals with FASD, is developing a plan of action for training individuals and groups around their region on the basics of FASD. TRUST members are also working to get more public service announcements on the radio, and on developing and advocating aftercare services for families that receive a diagnosis through their clinic. They are currently working on conducting a needs assessment for Ketchikan with the goal of better identifying gaps in training and the need for services. The Ketchikan team is dedicated to issues of prevention, and work in close partnership with other FASD projects in their community. In one recent session, the team decided to partner in the purchase of a breast pump that would be available to women who are breastfeeding and have been drinking! Thumbs up to all of the energy and creativity the Ketchikan community is generating. For more information about the diagnostic program or other FAS projects in Ketchikan, contact Jasmine Nelson at (907) 225-4061.∞

Alaska's FASD Diagnostic Team Network April 2003

Team Name	Service Area	Referral Criteria	Approximate Wait Time*	Contact Person
Ketchikan Area FASD Community Diagnostic Team	Ketchikan, Prince of Wales Island, and Metlakatla	Priority for ages 3-18 years *will accept 2 adult referrals per year	4 months	Jasmine Nelson, Ketchikan Indian Corporation 907.225.4061
Yukon -Kuskokwim FASD Diagnostic Team	Bethel and the Yukon Kuskokwim Delta, (58 tribes)	Priority for ages 3-18 Years * will accept adult referrals on a case by case bases	2-6 months, depending on the referral source	Sarah Pearson, Yukon Kuskokwim Health Corporation 907.543.6456
Kenai Peninsula FASD Multidisciplinary Team	Kenai Peninsula Priority, But will consider referrals outside of this area	All ages	Approximately 1 month	Margaret Parsons-Williams, Frontier Community Services 907.262.3144
Kodiak Compass Project	Kodiak Borough	All ages	Approximately 1-2 weeks to begin initial appointments	Naomi Foody, Kodiak Area Native Association 907.486.3671
Fairbanks Fetal Alcohol Community Evaluation Services	Fairbanks North Star Borough	Ages 5-14 years	Approximately 2-4 months	Sheree Dohner, Fairbanks Public Health Center, 907.451.1636
Multidisciplinary Developmental Disability Team (MD3 Team)	AHTNA region (Copper River Region)	All ages; Limited to Alaska Natives, however possible to receive consultation for non- beneficiaries	Approximately 1-3 weeks	Gay Wellman, Copper River Native Association 907.822.5241
Bristol Bay FAS Multidisciplinary Diagnostic Team	Bristol Bay Area	All ages	Approximately 2-3 weeks, depending on records availability	Luisa Hanson, Bristol Bay Area Health Corporation, 907.842.3404
Southcentral Foundation FAS Diagnostic Team	Priority to Anchorage, but will accept statewide referrals	Ages 3-18 years, limited to Alaska Natives	5-6 months	Mike Baldwin, Southcentral Foundation, 907.729.4250
Northwest Arctic FASD Diagnostic Team	Northwest Arctic Region and Point Hope	Monitoring for ages 0-3 years; Priority for ages 3-18 years; will accept referrals from any age	Team is in start-up process; waitlist information pending	Jeanne Gerhardt-Cyrus, NWASD/Maniilaq 907.475.2362
Sitka Neurodevelopmental Clinic	Sitka residents have priority, but will accept referrals from surrounding villages and other communities in Southeast Alaska	Ages 3 years and up	Approximately 2 months	Dyan Bessette, SEARHC 907.966.8629
Norton Sound FASD Diagnostic Team	Norton Sound Region (Nome and 15 outlying villages)	3 months to 6 years priority, but will accept all referrals	Team is in start-up process; waitlist information pending	Andrea Longpre-Macht Norton Sound Health Corporation 907.443.3494
Upper Tanana FAS Team	*info pending, team to be trained in 03/03	*info pending, team to be trained in 03/03	*info pending, team to be trained in 03/03	Tony Lee Upper Tanana Headstart 907.883.2672
Mat-Su Fetal Alcohol Resource Project	Mat-Su Borough	Priority for ages 3-18, will consider other referrals on a case-by- case basis	Approximately 1-2 months	Teresa Sprague, Mat-Su Services for Children & Adults, Inc. 907.352.1200

^{*} wait time refers to the time it will take upon submission of all paperwork to the time of first scheduled appointment.

FAQ: What is involved in the 4-digit diagnostic code?

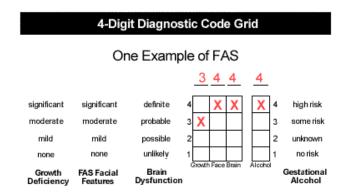
The 4-Digit Diagnostic Code is a tool developed by Drs. Susan Astley and Sterling Clarren at the University of Washington FAS Diagnostic and Prevention Network to assist in conducting a full, comprehensive diagnosis for individuals affected by prenatal exposure to alcohol. This method of diagnosis was selected for use by the Alaska FAS Diagnostic Team Network in 1998, after reviewing an enormous amount of data about diagnosing FAS and other alcohol-related birth defects.

Having a process that would provide an accurate, reproducible and unbiased method for measuring and recording the severity of exposure and outcomes in individual clients was critical as we began the process of establishing a number of diagnostic clinics across Alaska. In order to establish a statewide process, with consistency in diagnosis from community to community, this type of standardized diagnostic process was essential. We want to ensure that a diagnosis made in Kotzebue is the same as a diagnosis made in Ketchikan, providing comparable data for improved understanding about the extent and severity of FASD across Alaska.

The four "digits" in the code refer to the four key diagnostic elements of FAS:

- 1) growth deficiency;
- 2) the FAS facial features or "FAS phenotype";
- central nervous system (brain) damage/ dysfunction; and
- 4) maternal drinking during pregnancy.

The severity of each feature is then ranked independently (through a variety of exams, measurements and tests) on a 4-point scale with a 1 reflecting absence of the element, and 4 reflecting a strong or "classic" presence of the diagnostic element. In the example below, the 4-Digit Code is a 3444, which results in a diagnosis of fetal alcohol syndrome (medically termed "static encephalopathy, alcohol exposed). Once the patient receives a 4 digit code (of which 256 possible codes exist!) the number then relates to one of 22 possible diagnostic categories that include all of the possible outcomes that prenatal alcohol exposure presents. From this code, diagnostic teams can identify both cases where individuals meet the full diagnosis of FAS as well as cases where individuals have brain damage and documented prenatal exposure to alcohol, but do not have the growth deficiency or any of the associated facial features.



Team members typically needed to conduct a full 4-Digit Diagnosis include a physician, a psychologist, an occupational or physical therapist, a speech-language pathologist, and a parent navigator/family advocate. Having such a diverse group of professionals allows for a full understanding of the cognitive deficits, physical abnormalities, as well as the client and family needs. The use of this diagnostic approach has many benefits including increased precision and accuracy through the use of objective, quantitative measurements and specific case definitions, and better characterization of the full spectrum of alcohol-related disabilities (not just FAS).

Each of the 13 teams that represent the Alaska FAS Diagnostic Team Network has received training at the University of Washington in using and understanding the 4-Digit Diagnostic Code. To increase our long-term diagnostic sustainability in Alaska, the Office of FAS is funding the development of an instate training center that will be capable of preparing individuals to use this diagnostic method without having to travel out-of-state and to serve as a resource for ongoing development of diagnostic capacity across Alaska. Training center development will begin in July of 2003. For more information about this diagnostic process you can contact the DHSS Office of FAS, your local FAS Diagnostic Team (a complete listing of Alaska's diagnostic teams is included on the previous page) or the University of Washington's FAS Diagnostic and Prevention Network website at

Videotapes from FAS Summit 2002

During the November FAS Summit 2002, the CSAP FAS Center for Excellence graciously agreed to videotape the workshop presentations of our national presenters. We have now added, to our lending library, the following 90 minute videotapes of these presentations.

- Providing Substance Abuse
 Treatment of Individuals with
 FASD-
 - Candace Shelton, Presenter
- Preventing FASD: Motivating Alcohol-abusing Women into Sobriety-
 - Candace Shelton, Presenter
- Puberty and Sexuality: Ready or Not Here it Comes! Cheri Scott and Julie Gelo, Presenters
- Practical Strategies for School Success-
 - Julie Gelo, Presenter
- Receiving a Diagnosis of FAS for Your Child: Becoming an Educator and Activist–
 Kathleen Mitchell, Presenter
- Raising a Child with FAS: Achieving a Positive Mindset-Kathleen Mitchell, Presenter
- Therapeutic Alliances: What Helps and What Hinders From a Consumer & Family-Perspective-
 - Daniel Dubovsky, Presenter
- Utilizing a Socialization Coach:
 The Whys and HowsDaniel Dubovsky, Presenter
- FAS is Not for Children Only:
 Strategies for Adolescents and
 Adults with FAS-
 - Daniel Dubovsky, Presenter
- The Use of Medication for Treatment of Mental Health Difficulties: An Overview-Daniel Dubovsky, Presenter

All of these videos are available for loan from our library by calling Sherrie at (877) 393-2287.

Alaska Women's Recovery Project

The Alaska Women's Recovery Project (AWRP), based in Anchorage, was initiated through Southcentral Foundation's Dena A Coy Addiction and Mental Health Treatment Program for women. It is supported by a grant from the Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Substance Abuse Treatment (CSAT).

The history behind the development of this project is directly related to the experiences and lessons learned while working with women in recovery from alcohol or drug addiction. These women have shared their experiences of the challenges they faced on their path to recovery. The AWRP core committee of women in recovery is now the driving force, the wisdom and inspiration, which provides the hard work behind the development and implementation of recovery support activities.

Participating members of the Alaska Women's Recovery Project support the mobilization of women of all ages and ethnic backgrounds, in various phases of recovery from alcohol and drug addiction, to move from a position of anonymity to active participation and empowerment.

The mission of the Alaska Women's Recovery Project is to give women in recovery a voice to provide input to related programs and services, raise community awareness about substance addiction, treatment, and recovery, provide recovery support activities for women and their families, and challenge the stigma and bias often associated with women in recovery.

The overarching goal of the Alaska Women's Recovery Project is to work with the community to develop a positive recovery climate.

The women who give their time, wisdom, and talent to carry out this mission are joining a new national trend known as "Join the Voices of Recovery" and "Changing the Conversation," in which recovering men and women are choosing to move beyond anonymity to make a difference, and take action to address recovery issues and obstacles in their communities.

The AWRP core committee members are making an impact since they joined forces in the spring of 2002. Intensive and successful outreach activities have included a community-wide gathering, attended by 100 women, who identified recovery strengths and support needs, a community-wide Recovery Month Celebration in September, a Holiday Sobriety Celebration, featuring crafts, music and food, for women and their families, and a weekly *Women Supporting Women in Recovery* group. In addition, International FAS Awareness Day was an opportunity for the AWRP Committee to collaborate with community organizations to find creative and innovative ways to support sobriety throughout pregnancy.

The women of the Alaska Women's Recovery Project know that great things can be accomplished when women reach out and help other women. If you would like to learn more about the Alaska Women's Recovery Project, please call (907) 729-5090.≫

Did you see us at the Super Bowl?

If you are one of the thousands of football enthusiasts in Alaska you may have seen our FASD public education commercials during this year's Super Bowl! Our contractor, Nerland Agency, secured two (2) 30-second spots for the most watched TV event of the year to air our messages, I Have the Power to Prevent FAS and Thankfully there are people who will help her... Are you one of



them? Phase I of our campaign premiered in September and has been airing since that time, with great results.

We are now gearing up to kick off phase II of our campaign expanding on the themes meant to empower women who are drinking to seek help and asks friends, family and community, "Are you someone who will help"? Our second phase will continue to generate awareness for those who may not know drinking during pregnancy can cause brain damage to their developing baby and to encourage the community to support pregnant women to make healthy choices. We have developed two TV public service announcements (PSAs) and two radio spots we believe will have a very effective reach. Both the TV and Radio announcements will begin airing statewide in May. Both ads will also be available online for download at www.hss.state.ak.us/fas/ as are the ads from phase I.

To date, we have been very pleased with our airtime of these radio and TV PSAs. Between September and December, 2002 the Office paid for media spots in the amount of \$39,300 and received donated PSA spots (radio and TV) equaling \$42,185. We applaud the commitment of the media industry to increasing awareness about the dangers of drinking alcohol during pregnancy!

The Office of FAS has also developed two brochures, two posters and message pens that are consistent with our themes and are available for dissemination statewide. If you would like some of the materials for your agency, please contact the Office of FAS toll-free at (877) 393-2287.≫

Correction: In our last news letter the website for DFYS Independent Living was listed incorrectly. The correct web site is: www.hss.state.ak.us/dfys/independentliving

Brain Gym Helps Increase Neural Pathways

Brain Gym® is a simple, fun and dynamic way to increase learning and performance for people of any age or ability. Based on an understanding of the interdependence of physical development, language acquisition and academic achievement, Brain Gym® was developed by Dr. Paul Dennison in the 1970's. As owner/operator of California reading clinics, he discovered that including movement in a students' routine increased learning and performance.

Extensive research on brain function shows that directed movement (Brain Gym® activities) increase neural pathways in the brain, thus creating "stress-free" learning! This is great news for "students" of any age, and especially for the FASD community. Even when brain damage is present, the possibility that Brain Gvm® may increase the brain connections is encouraging. Depending on the extent of damage. Brain Gym® can help "raise the bar" of learning and performance for anyone, with improvements to concentration, memory, organization skills, language and number skills, reading, writing and more!

Want to learn more? The book Smart Moves by Dr. Carla Hannaford is a straight-forward, easy to read book text that tells why movement is vital to our life, and includes some basic Brain Gym® movements. Additional information about classes, instructors and Brain Gym® is available at www.learningdynamics.us and www.braingym.org.

Data Collection in Progress—What is it telling us?

Since 1999, the Alaska FAS Project has been assembling a broad and diverse collection of data, numbers, surveys and other information to begin weaving together a picture of what is happening in Alaska with regard to prenatal exposure to alcohol and related birth defects. One of our primary goals has been, and continues to be to "document our progress and evaluate program outcomes" to help us better understand where we have been, where we are now, and where we need to go in the future. While much of our data is still preliminary and not fully analyzed, it is beginning to give us great information that will help us plan our ongoing state FASD agenda.



KABB

Last spring we began distribution of the FAS Knowledge, Attitudes, Beliefs and Behaviors (KABB) survey—a survey designed to better understand what people across the state of Alaska know about FAS, alcohol and pregnancy, and resources to both prevent and improve services related to fetal alcohol spectrum disorders. The survey was designed to ask questions related to a persons overall knowledge, their attitudes and beliefs and how they would react or behave related to this issue. The goal for the survey was to look at the attitudes of the general public (through a phone survey) and the varying attitudes of different disciplines (through a paper survey). A total of eight (8) separate surveys were completed for pediatricians, OB-GYNs, family practice physicians, public health nurses, social workers, substance abuse counselors, corrections workers and educators. Each survey had the same 12 core questions and then 8-10 specialized questions related to their discipline. A total of 4,448 surveys were mailed with a return rate of approximately 73%. For the general public phone survey (using the same 12 core questions) a total of 1,119 phone surveys were completed from across Alaska.

All data entry has been completed and full data analysis is now underway. To give you an idea of what the survey results are showing us, here are a few questions, with response rates:

In your opinion, is it okay for a pregnant woman to have an occasional alcoholic beverage?

- 83% of the general public responded "No"
- 88% of all professionals responded "No"
- 78% of all medical providers responded "No"
- ≤ 59% of all OB-GYNs responded "No"

Do you think it's her own business if a woman drinks alcoholic beverages during her pregnancy?

- 32% of the general public responded "Yes"
- 13% of all professionals responded "Yes"
- № 15% of all medical providers responded "Yes"

People with Fetal Alcohol Syndrome have a set of birth defects.

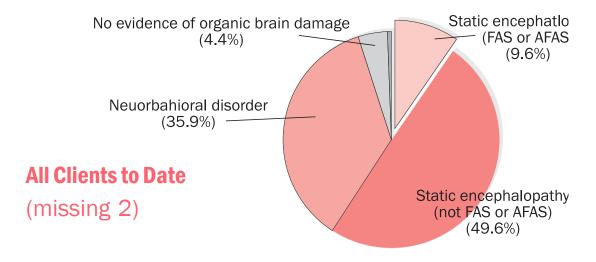
- 87% of the general public responded "Agree"
- 86% of all professionals responded "Agree"
- 85% of all medical providers responded "Agree"

Diagnostic Data

Another area where we are collecting a great deal of data is through the Alaska FAS Diagnostic Team Network. Currently there are 13 community-based diagnostic teams that comprise the Network, with 10 teams providing diagnostic services at this time. Each quarter teams are required to submit data forms for each diagnosis completed. From July 1999 through September 2002 a total of 341 diagnoses have been completed by nine of the diagnostic teams. Of these clients 43% are female and 57% are male and the median age at diagnosis is 11.5 (with a range from 3 years to 29 years of age).

Of these completed assessments, 33 or 9.6% received a diagnosis of fetal alcohol syndrome (FAS) while 293, or 85.5%, received a diagnosis indicating evidence of organic brain damage (static encephalopathy or neurobehavioral disorder). This data clearly supports our anecdotal data indicating the majority of individuals affected by prenatal exposure to alcohol do not have full FAS, but do have significant levels of brain damage—truly a hidden disability.

For those individuals who have completed the diagnostic process, 13.7% are in the custody of one or both biological parents; 25.1% are in the custody of adoptive parents or legal guardians; and 37.6% are in the custody of the state through DFYS. The primary referral sources thus far are DFYS (29.2%); caregivers (23.3%); medical providers (15.2%); mental health providers (11.7%); and schools (4.1%). Finally, the median number of days from referral to first appointment is 41 days; 24 days from first appointment to completion of diagnosis; and 114 days from referral to completion of diagnosis.



Alaska Birth Defects Registry

In an effort to improve our states overall data on the prevalence of fetal alcohol syndrome and other birth defects resulting from prenatal exposure to alcohol, the Office of FAS is working in partnership with the Alaska Birth Defects Registry (ABDR) and the FAS Surveillance Project. Our belief is that if we increase the overall knowledge about FASD among all medical providers (those who report to the ABDR) and we increase the state's capacity to assess and diagnose individuals with these disabilities, we will have improved and more accurate data about the prevalence of FAS and other alcohol-related birth defects in Alaska.

To ensure that the diagnostic teams report to the Birth Defects Registry, a copy of each data form completed by the teams is sent to the ABDR. By including this step for our diagnostic teams, we will be able to track how many reports to the ABDR are made exclusively through our diagnostic teams, and not through other sources.

The Birth Defects Registry receives data for children starting with birth years 1990 to date (our diagnostic teams have assessed individuals with birth dates 1957 through 2002). As of October 1, 2002 the ABDR received 1315 reports for the ICD-9 code 760.71 (alcohol affecting fetus via placenta or breast milk; including fetal alcohol syndrome). Of that number, 1136 children (or 86%) were reported by sources other than FAS Diagnostic Teams; 126 children (9.58%) were reported by a FAS Diagnostic Team only; and 53 children (4%) were reported by a team and at least one other source.

These data are encouraging. Almost 10% of the children reported to the ABDR with ICD-9 code 760.71 were identified by diagnostic teams and had not been reported by other sources. Reporting to the Birth Defects Registry for ICD-9 category 760.71 increased 40% from fiscal year 2001 (125 reports) to fiscal year 2002 (177 reports). We are hopeful that our increased awareness about FAS and birth defects resulting from prenatal exposure to alcohol is contributing to this overall increase in recognizing the importance of reporting to the ABDR and documenting maternal drinking during pregnancy.

Dates to Remember April

FAS Update/Spring 2003

22-23 Early Childhood Behavioral Health Institute

Location: Anchorage Hilton Hotel. For information contact Kathy Allely, (907) 269-5231 or *kathy_allely@health.state.ak.us*.

24-25 Full Lives; Moving Forward Together Direct Support Conference-2003:

Location: Marriott Hotel, Downtown Anchorage. For information (907) 272-8270 or www.alaskachd.org/fulllives/.

26 Micro-Enterprise Development Workshop

Location: UAA Commons, Anchorage. For information (800) 243-2199 or www.alaskachd.org

May

5-7 Annual School on Addictions: Serving the Whole Person.

Sponsored by the Substance Abuse Directors Association of Alaska.

Location: Sheraton Hotel, Anchorage. For information contact SADA, (907) 770-2927 or www.meetingresults.com/projects.php.

30-31 Eye of the Storm: A training about FASD. Deb Evensen, Trainer.

Location: Kenai River Center, Soldotna. For information contact Vickie or Margaret at (907) 262-6331 or (800) 819-8194.

June

2-6 20th Annual Rural Provider's Conference:

Climbing the Mountain of Sobriety and Hope.

Location: The Alaska Vocational Technical Center, Seward, Alaska. For information contact Marian Estelle, RurAL CAP, (800) 478-7227 or www.ruralcap.com/rpc.shtml.

23-27 FASD Training Certification Program.

Location: UAA Campus, Anchorage. For information contact the Office of FAS, (877) 393-2287or www.hss.state.ak.us/fas/

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